

A handbook for people who have injected drugs



Introduction

This handbook has been written for current and ex-drug injectors. It gives information and advice about the hep C virus, and the tests you can take to see if you've been infected.

It also explains how to protect yourself from the virus if you're negative. If you are hep C positive, it explains the medical care you might need and what you can do to reduce health problems.

It's best if you can go through it with a healthcare worker so that they can explain anything that you don't understand (your keyworker, doctor or practice nurse should be able to help).

What is hepatitis C?

Hepatitis C (known for short as 'hep C') is a virus that causes liver damage. There are other viruses that attack the liver such as hepatitis A and B, but hep C is the most common one that injecting drug users get.



Viruses are tiny – if a single virus was blown up to be the size of a marble ... a syringe at the same scale would be 75 miles high!

Viruses hijack cells in the body to produce millions of copies of themselves, which then break out of the cell, and infect other cells. Hepatitis C lives in blood, and in the liver.

How is it spread?

The hepatitis C virus is present in the blood of someone who is infected.

It is spread when blood from an infected person gets into the bloodstream of an uninfected person.

The most common way this happens is when a needle or syringe that has been used by someone who is infected, is used by someone else.

Needles and syringes are by far the most risky thing to share, but there may also be enough blood on spoons and filters, and in water that has been used to clean a syringe, to infect someone who uses those items shortly after someone who has the virus has used them.

So, if you have the virus, other people are at risk if your blood gets into their bloodstream.

If you are still injecting, there is a risk of passing infection to the people you inject with if they share your injecting equipment – either on purpose, or by accident.

You should also not share toothbrushes and razors.

The risk of passing on hep C through sex is very much lower than it is through drug injecting, but practicing safer sex (using a condom) prevents sexual transmission of hepatitis C, and other diseases.

Like HIV, hep C is not transmitted by social contact like sharing cups, shaking hands, hugging, or kissing.

Some people may have a mild flu-like illness shortly after they are infected, but for most, it takes years before the first symptoms appear.

So, if you've been at risk: get tested!

If you think you may have shared a needle, syringe, spoon, filter, or mixing water then you may have caught hep C.

You should get tested to see if you are hep C positive because if you are positive:

- There are treatments that can clear the virus from your body
- You can make sure no one catches the virus from you
- You can reduce your alcohol consumption to protect your liver

And if you find you are negative you can:

- Stop worrying; and
- Make sure you don't catch the virus.

There are **two types of test** that can tell you if you've had hep C in the past and if you've still got it now.

The antibody test

The first test will show if you have ever had the virus. If you are exposed to the virus, your body makes 'antibodies' to try and fight it off. These antibodies remain even if the virus has gone.

A blood sample is required, usually collected by needle and syringe but some areas can offer a 'dried blood spot' test, which just needs a few spots of blood from a finger-prick - so it's very easy to get tested.

The PCR test

If the antibody test is positive, a blood test called the 'PCR' test will tell if you have got the virus now.

What happens if I have a hep C positive PCR test?

You will need further tests to see how your liver is working, and whether you have any liver damage.

The medical team will discuss with you the options for treatment to get rid of the virus, and what you can do to reduce the damage to your liver.

Dealing with a positive result

If you have just found out that you are hepatitis C positive, don't panic. There is treatment available to get rid of the virus, and there is a lot that you can do to protect your liver from the damage an infection can cause.

For some, hepatitis C causes little problem. For many though, it can be very serious, leading – over years – to severe liver disease and even to liver cancer or liver failure. The outcome for someone who is infected depends on a number of things. The most important things are:

- how much alcohol you drink;
- whether you get treatment for infection; and
- which type of hepatitis C virus you've got.

You can do a lot about the first two of these - alcohol consumption can be reduced or stopped, and there is effective hepatitis C treatment available on the NHS.

The National Institute for Health and Clinical Excellence (NICE for short, the organisation that decides which treatments should be funded) has approved 'combination therapy' for hepatitis C infection, when a doctor thinks it appropriate, so it should be available locally.

Some people find the treatment itself difficult and may need time to prepare before starting.

You may not have to stop injecting completely to get treatment. But, the doctor responsible will want to be sure that treatment is still appropriate e.g. any injecting is carried out with sterile equipment, and that your lifestyle makes treatment practical.

If you find out you are hep C positive, there are three things you must do:

 You need to make sure that you don't put yourself at risk of catching hepatitis C again (because infection with more than one strain of the virus can make the disease much worse)

If you are injecting it means that you should always use a clean needle and syringe and never share water, spoons, or filters.

Never 'frontload' or 'backload' your syringe from someone else's and generally be blood aware: be very careful about your (and other people's) blood every time you inject.

2. If you drink alcohol, take medical advice

Because hepatitis C and alcohol both damage your liver, it's really important that you cut down your alcohol intake as much as you can. Whoever carries out your hepatitis C test should be able to put you in touch with alcohol support services to help you cut down your drinking.

3. Find out about getting treatment

Effective treatment for hepatitis C is available. It doesn't work for everyone, but it is worth thinking about seriously. It is possible that treatment can get rid of the virus, before liver damage occurs. The type of hepatitis C virus you have affects how successful the treatment will be.

The effects of hepatitis C infection

When the virus has damaged the liver, the symptoms people get include:

□ tiredness □ depression

□ aches □ anxiety

nausea memory loss.

stomach ache

But, these symptoms are common - having some or even all of them, doesn't necessarily mean you have liver damage. If you are concerned, talk to your doctor or drug worker.

After you're infected, what actually happens can vary, and depends on a number of factors, such as which type of hepatitis C you have, how much alcohol you drink, and whether you get treatment.

- Current evidence suggests that around one in five of the people who get infected with hepatitis C will naturally get rid of the virus (but they may still catch it in the future if they share again with someone who is infected).
- Most of those who remain infected will eventually develop liver damage – for some of them, this damage will be very serious.

The longer the infection is untreated, the more likely that liver damage will occur. After a positive test, it is very important to find out whether you have liver damage and whether you need treatment to get rid of the virus.

Hep C treatment

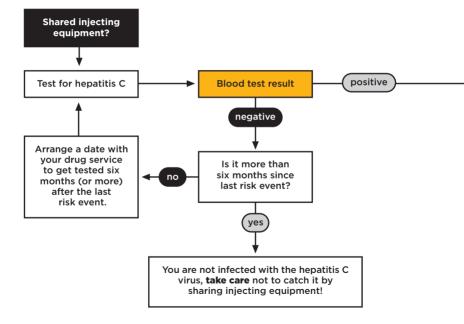
The treatment is called combination therapy. It consists of two drugs: interferon and ribavirin, which combine to get rid of the virus.

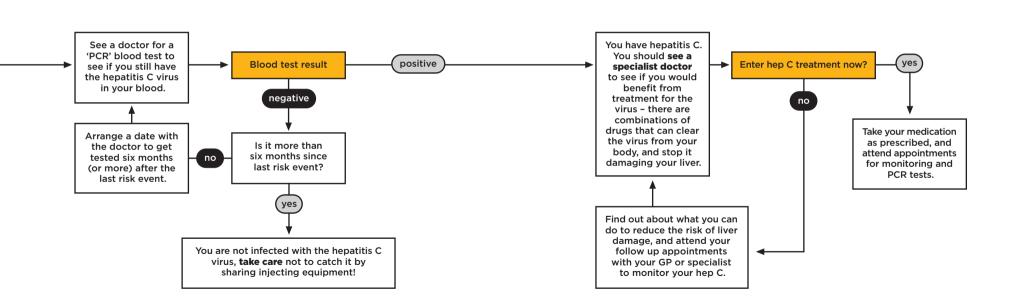
The treatment is effective, but some people can find the side effects difficult to cope with.

You can still get treatment if you are using drugs. What is most important, is that your lifestyle makes treatment a practical option and that you are not likely to get re-infected with hepatitis C.

The care pathway

This 'flow diagram' shows you the various stages involved in testing and treatment for hepatitis C.





The following organisations have helplines, websites, and publications that might be of interest:

Hepatitis C trust

www.hepctrust.org.uk Helpline 0845 223 4424

The British Liver Trust

www.britishlivertrust.org.uk Helpline 0800 652 7330

The UK Hepatitis C Resource Centre

www.hepccentre.org.uk Telephone 0870 242 2467

There is also detailed information in the booklet 'Guidance for the prevention, testing treatment and management of hepatitis C in primary care', available from www.smmgp.org.uk



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Written by: Noel Craine, Jon Derricott and Andrew Preston.

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